

Spring 2020 mswa.org.au





WE KNOW NEURO

WILSON CENTRE

29 Parkhill Way 9365 4888
Fax 9451 4453
Freecall 1800 287 367
See Health Team Dept contacts on this page

MEMBER SERVICES DIRECTORY

GENERAL MANAGER - MEMBER & CLIENT SERVICES

Nicola Washington 9365 4840

MANAGER OF ALLIED HEALTH SERVICES
Carol Chong 9365 4873
NDIS TEAM 9365 4824

OUTREACH GROUPS

Wilson Outreach 9365 4830
Beechboro Lodge 9377 7800
Southside Outreach 9592 9202
Albany Outreach 6154 5149
Bunbury 6454 2800

GENERAL MANAGER - STRATEGIC SUPPORTS AND RESIDENTIAL OPTIONSSue Shapland 6454 3174

MARGARET DOODY RESPITE HOUSE
Manager, Alimul Tasin 9385 9574

FERN RIVER ACCOMMODATION

Manager, Danuta Figurska 9356 2747

HAMILTON HILL ACCOMMODATION

Manager, Jo Nouwland 9331 5780

TREENDALE GARDENS RESPITE & ACCOMMODATION

Manager, Linda Kidd 9725 9209

BUTLER SUPPORTED ACCOMMODATION FACILITY

Manager, Chris Rush 6154 5120

CONTACT US

If you would like to comment on anything you read in this *Bulletin* please email **bulletin@mswa.org.au** or write to **MSWA**, Locked Bag 2, Bentley DC WA 6983

General feedback or complaints please contact Liz Stewart 6454 3173 or

feedback@mswa.org.au

EDITORIAL COMMITTEE

Greg Brotherson (Editor), Ros Harman (Guest Editor), Marcus Stafford (CEO), Paul Cavanagh, Sue Shapland, Nicola Washington, Libby Cassidy, Jamey Claffey, Carol Chong and Geoff Hutchinson.

The Editor welcomes unsolicited submissions.

All articles are subject to a reviewing process. The views expressed are those of the authors and do not necessarily reflect the view of MSWA's staff, advisors, directors or officers.

NURSING

Our MS nurses are usually the first point of contact after the neurologist's diagnosis of MS. VANISHREE CHETTI, MANAGER: 9365 4818 OR COMMUNITY NURSE: 9365 4888

PHYSIOTHERAPY

Our team provides treatment interventions to develop and maintain mobility and function. DAVE HATHORN, MANAGER: 9365 4837 OR PHYSIO DEPARTMENT: 9365 4834

OCCUPATIONAL THERAPY

Occupational Therapists enable Members to continue their work and other interests for as long as possible through advice, aids and equipment.

MANAGER: 9365 4804 OR OT DEPARTMENT: 9365 4888

SPEECH PATHOLOGY

Our Speech Pathologists assess, diagnose and create individualised treatment programs for Members who experience swallowing and/or communication difficulties. PAMELA WINDRAM, MANAGER: 6454 3140

DIETETICS

Dietitians are university-qualified nutrition experts who promote general health and disease prevention/management through dietary changes.

PAMELA WINDRAM, MANAGER: 6454 3140

COUNSELLING, PEER SUPPORT & HEALTH EDUCATION

Talking with a Counsellor creates a safe, respectful and confidential environment for you and those close to you to explore options, create change or gain understanding about your life.

TO MAKE AN APPOINTMENT PLEASE CALL: LISA PAPAS, MANAGER: 9365 4836 OR COUNSELLING DEPARTMENT: 9365 4811

SOCIAL WELFARE

Social Welfare Officers assist Members and their families to access services and supports to remain living independently at home. They specialise in case management, advocacy and sourcing funding options.

KATH KNIGHTS, MANAGER: 9365 4835

COMMUNITY SUPPORT

We provide long-term and time limited in-home supports including assistance with personal care for people with MS, to help them remain in their homes. Care and supports are provided through a combination of funding from the Department of Communities - Disability Services, and our own fundraising efforts.

MANAGER: 9365 4851

CUSTOMER ENGAGEMENT DEPARTMENT

Our experienced teams will provide you with personalised support right throughout your NDIS journey. From helping you to access the NDIS to working with you to get the most from your plan, our trained staff are here to help.

GEOFF HUTCHINSON, MANAGER CUSTOMER ENGAGEMENT: 9365 4879

CAMPS & RECREATION

MSWA provides separate recreation camps for Members, carers, and families, primarily funded by Lotterywest, and for a nominal cost to participants. These camps provide a break from daily routines, and strengthen friendships and support networks.

COORDINATOR FOR CAMPS & RECREATION: 9365 4843

AGED CARE

MSWA delivers all levels of Home Care Packages to eligible people with a neurological condition who are over 65. Services are delivered by staff specifically trained in home care for older Australians who are living with a neurological condition.

WENDY BROWN, AGED CARE COORDINATOR: 9365 4807

CONTENTS

I ETTED COOM THE CRITCO

LLITER I ROM THE EDITOR	
FROM THE DESK OF THE CEO	. 4
NEW MSWA PRESIDENT	5
MSWA PROPERTY UPDATE	5
GENERAL MANAGER STRATEGIC SUPPORTS	
AND RESIDENTIAL OPTIONS	6
GENERAL MANAGER	
MEMBER & CLIENT SERVICES	7
RESEARCH ROUND UP	3-10
RESEARCH IN FOCUS	. 1
INDEPENDENCE DAY	. 12

SUPPORT COORDINATION -
HELPING YOU NAVIGATE YOUR NDIS PLAN13
TAKING IN THE BREATH14
EXERCISE PHYSIOLOGY AT MSWA15
FOR RICHER, FOR POORER16-17
VISITING NARELLE18
A BEAUTIFUL LIFE 20-21
MINDFULNESS FOR BEGINNERS 22
TAKING A BREAK IN OUR RESPITE HOMES 23
THE AUSTRALIAN MS LONGITUDINAL STUDY
(AMSLS) IS LOOKING FOR PARTICIPANTS 23

CAMPS ARE BACK!	24	-25
MEDICATION UPDATE		25
VOLUNTEER UPDATE		26
DID YOU KNOW?		27
PROTECTING YOURSELF AND OTHERS		
FROM THE FLU AND COVID-19		28
FEEDBACK AND COMPLAINTS		29
OUTREACH NEWS		
RECENT FUN AT TREENDALE GARDENS		34
JAYNE O'SULLIVAN - 23 YEARS OF SERVICE		35



This spring edition of *Bulletin* is full of interesting articles. We are very happy to be able to report that – after taking precautionary measures earlier in the year to prevent the spread of COVID-19 – we have been able to open Outreach centres again. Many of our Customers have been enjoying the social interaction of Outreach groups and have benefited by being able to gather with friends again. Outreach groups around Perth and country centres have enjoyed many interesting activities in the second part of this year.

In this edition you will read about camps that have been held for Members which allow people to get away from their usual routine and enjoy some fun. One camp was held at Treendale Respite Centre and another at Woodman Point. You will also read about Support Coordination, which is a service provided by MSWA to help people understand their NDIS plan and develop skills in utilising it.

The organisation's Annual General Meeting was held very recently and it was great to hear that despite the Coronavirus, our most recent Mega Home Lottery sold out in record time, ensuring that we remain profitable and able to continue to serve the needs of people with multiple sclerosis and other neurological conditions.

At the AGM, George Pampacos announced his retirement from the role of President of the MSWA Board after serving two terms. George was an excellent president and brought many skills to the role, seeing MSWA successfully through six years of growth and prosperity. He will be missed and we wish him well as he pursues other interests and continues to further his career.

We also had a report from CEO, Marcus Stafford, at the AGM who updated us on the continued success of MSWA in this testing year. MSWA staff took early and stringent precautions to protect against the virus, and it has served us well. No one associated with MSWA is known to have become infected, and we have continued to grow and serve our Customers well.

In this *Bulletin* you will also read an article about long-term Member, Narelle Taylor, who many of you will remember as a regular contributor of humorous articles in this magazine. Narelle is doing very well and her story is a very interesting one.

I hope you enjoy this fine spring weather and are able to get out into nature, where you can breathe deeply of the fresh air. I wish you all well.



ROS HARMAN GUEST EDITOR

FROM THE DESK OF THE CEO



MARCUS STAFFORD

As I pen this contribution to *Bulletin*, MSWA has just held its Annual General Meeting, in which the Board of Directors welcomed Clients and staff to our Wilson Services Centre to hear a summary of our performance in the last financial year.

In difficult times brought about by Covid-19, the year delivered record-breaking results. These included financial performance, the delivery of services, support to our Customers, our contribution to research and our increasing property footprint.

As an organisation looking to the future, we strive for continuous improvement, and looking around us, we recognise that the disability sector in Australia is challenged by the demands of funding, workforce and skills shortages, together with the safe delivery of quality services whilst meeting demand.

My philosophy in approaching these ongoing challenges is to be measured and thoughtful, mindful of the present, but with an eye to the future. This philosophy has never been so apt and so tested as we have manoeuvred our way through the uncertainties of 2020. The team effort was never more important and all stakeholders, including the Board, management, staff, volunteers, Members and Clients should take a bow in acknowledgement of the critical part that they played.



George Pampacos, with his parents, Barbara and Michael, at the MSWA Annual General Meeting 2020.

The recent Annual General Meeting was also an occasion to say *au revoir* to George Pampacos, who has decided to retire as President of MSWA, after six distinguished years as President and ten years on the Board. Having been brought up with a mum living with MS and driven by a desire to make a difference, the results under George's leadership of the Board speak for themselves.

At the Annual General Meeting, I talked about the sensible distinction between the role of the Board and the role of management; that separation of powers, with mutual checks and balances that is designed to protect us all.

Yet, as I bid farewell to George, the President, with both my respect and appreciation for the role he has performed, it is so pleasing that I can say that I look forward to seeing George, my friend, in the years to come.

Since the AGM, the Board has accepted Ros Harman's nomination as President. Her wide-ranging contribution to MSWA makes her a worthy President to take MSWA on the next stage of its journey.

NEW MSWA PRESIDENT



ROS HARMAN MSWA PRESIDENT

It gives me great pleasure to announce that, following George Pampacos' resignation from the position of President of the Board of MSWA, I have been endorsed as his replacement.

George served on the Board for 10 years, 6 of which were as President and I would like to thank him for his service during this time. He was an excellent President and saw the organisation through a period of growth and stability. He also served MSWA very well as a representative to MS Australia and was instrumental to the

reorganisation of MS Research Australia into a subsidiary of the MSA Board. I am sure you will join me in wishing George well in his future and expect he will continue to be successful in both his professional and personal life.

As President, I am proud to be the first woman living with MS in this role. I have a long history of 32 years with MSWA, including 16 years on the Board. I am confident I can work with the Board as we move into the next few years.

I would also like to take this opportunity to congratulate our CEO, Marcus Stafford AM, on his honorary doctorate recently awarded by Edith Cowan University. This recognition for his service to MSWA and elsewhere is well deserved and we are very lucky to have had him at our helm for the past 17 years. I look forward to working with him into the future.

Warm regards,

Ros Harman MSWA President

MSWA PROPERTY UPDATE

MSWA MONTARIO QUARTER

The development of a new High Support Accommodation Facility in Montario Quarter (Shenton Park) will begin construction in late 2021.

This new 20-unit Facility will provide long-term supported accommodation options, in a homely environment, for adults living with a neurological condition, with 24-hour care provided onsite.

The Facility will also accommodate the long-term Quadriplegic Centre residents who currently reside at the Quad Centre in Shenton Park.

Completion of MSWA Montario Quarter is estimated for end of 2023.

MSWA ALBANY

MSWA has begun construction of a new multipurpose \$7m Facility for people living with a neurological condition in Albany.

The new High Support Accommodation Facility and Services Centre will replace the existing Albany Centre which has been solely providing services and supports to locals for over 20 years.

The new High Support Accommodation Facility will feature 10 fully accessible units to cater for MSWA's high support Customers with 24-hour care provided on-site.

The new Services Centre will continue to provide MSWA's regional Customers access to services including physiotherapy, occupational therapy, nursing, counselling, speech, dietetics and outreach.

It is expected the new High Support Accommodation Facility and Services Centre will be completed early 2022.

STRATEGIC SUPPORTS AND RESIDENTIAL OPTIONS



SUE SHAPLAND RN, BN, MSCN GENERAL MANAGER STRATEGIC SUPPORTS AND RESIDENTIAL OPTIONS

"The struggle you're in today is developing the strength you need for tomorrow.

Don't give up."

Robert Tew.

I thought this quote is probably quite relevant for so many of us as we face the many challenges that present to us personally and as a society. Obviously, the current challenge remains COVID-19, and the life changing restrictions it has imposed on us. Thankfully Western Australia has been less impacted by this highly infectious disease but things could have been very different had we not heeded sound advice and restricted our activities and followed the key preventative messaging. But we must not get complacent as a second wave is a real risk and the impact could well be greater.

MSWA continues to keep hard at work, and we have much to be gratefulfor, and to look forward to. The recent MSWA Mega Home Lottery was an amazing success and one of our Customers and her husband took out the grand prize! Read about their story in this edition of *Bulletin*. We are contributing another record amount to neurological research again this year – \$4 million, supporting researchers looking at the cause, better treatments and hopefully cures for MS and other neurological conditions.

We are very proud of our capacity to support the research efforts which bring hope and better outcomes for so many people and their families, both now and into the future.

We continue to be impressed and proud of the great research teams we support and collaborate with right here in WA, they are all quite innovative. There is a passion to get results and have a positive impact for those living with neurological conditions, whether that's through discovering new information about the cause and risk of developing a condition or evaluating new therapies and identifying those who can most benefit; stay tuned for our updates.

We are expanding our High Support Accommodation program as previously mentioned and we are glad things can now start to get back on track. We have recently commenced construction of the Albany Facility (10 units) and adjoining Services Centre. We are in the planning stage for our Shenton Park development; 20 units will be on that site.

Our Respite facilities re-opened after a COVID-induced hiatus. The staff were so excited to welcome our Customers back to City Beach and Treendale. Many Customers were glad to book an essential break once again from their daily home routines and, for their carers, a well-earned break to recharge their batteries.

2020 has been a real challenge for Australia, and indeed the world, not only due to COVID-19 and the impact that has had on our freedom of movement and, for many, their employment opportunities, but also, the ongoing forces of nature with bushfires and storms wreaking havoc. Hopefully things will get back to a semblance of normality and 2021 can be a year of calm and safety. As we can't travel overseas, or in some cases even interstate, Christmas may be different but hopefully we will get a chance to enjoy the company of our family and friends and refresh ready for the new year. One positive outcome has been families reconnecting and people again enjoying home cooking and crafts. So be prepared for homemade gifts this year!

MEMBER & CLIENT SERVICES



NICOLA WASHINGTON GENERAL MANAGER MEMBER & CLIENT SERVICES

Welcome to the spring edition of our Member & Client Services *Bulletin*.

Wonderful to see us getting back to some warmer weather and lovely sunny days.

As we continue to be lucky in WA at keeping COVID-19 under control, it is also good to know that we are nearly through the flu season.

Understandably, it is still a difficult time for those missing families across states and internationally, as there still remains some restrictions on our borders. It does highlight the importance of staying connected and I encourage you to use the resources available to you through MSWA, and contact us if you need any help or advice.

Our Outreach team have been busy ramping up activities over the past few months. There have been some great activities happening, including a morning of live music at Wilson recently, it was great to see spirits lifted and everyone having fun. See more on Outreach on page 30.

We have recommenced our group sessions, including coffee catch ups and support groups, so keep an eye out for the latest information on dates and times or contact us if you would like to know more about what is coming up.

Great news is that our Albany build is under way for our new Accommodation and Services Centre. This will be an exciting project through 2021, managed by Andrea Taylor. Regular updates will be provided on the progress with the build.

Here is the NDIS WA quarterly results snapshot:

- / 33,062 participants have entered the Scheme since July 2013. An increase of 5,174 since last quarter.
- / Increase in active participants receiving supports for the first time rising to 15,017.
- / 6,644 plans have been reviewed this quarter.
- / Average days to complete first plan after the access requirements have been met (age 7 and over) – 120 days
- / Plan utilisation was 63% over a six month period with 17% of regions in Western Australia falling below the benchmark.
- / North East Metro continues to have the highest number of active participants (5,556) while Goldfields-Esperance continues to have the lowest (502).

The number of participants in the NDIS continues to grow and the NDIA continues to report on the ongoing reviews of the program to create flexibility for participants.

The latest news on the introduction of independent assessments is covered by Geoff Hutchinson in his report on page 12.

We want you to get the best out of your NDIS plan to access the services you need and choose to receive. Our Customer Engagement team are actively contacting our Customers to assist with service delivery, but if you have any questions regarding your NDIS plan please do not hesitate to contact ndisenquiries@mswa.org.au

On a final note, I need to advise that we have made the decision to postpone the 2020 Members' and Volunteers' Christmas party until next year. I know that many of you will be disappointed, but this decision has been made with the safety of everyone in mind. Our plan is to hold 'Christmas in July' in 2021, when we hope to see COVID-19 under more control across the globe.



FROM THE NEUROLOGY RESEARCH REVIEW

Read more at: researchreview.com.au

Association between tumor necrosis factor inhibitor exposure and inflammatory central nervous system events, Kunchok A et al. (Issue 58, 2020)

nested case-control study evaluated the association between TNF inhibitor exposure and inflammatory CNS events patients with autoimmune disease. 106 patients with an inflammatory demyelinating or non-demyelinating CNS were matched for age, type of autoimmune disease, and sex with 106 controls. 60% of cases and 40% of controls were exposed to TNF inhibitors.

Comment: This study shows an increase of demyelinating and non-demyelinating inflammatory CNS disease in patients on TNF inhibitors; not unexpected given these drugs worsened MS when used in clinical trials.

There appeared to be a greater risk of CNS disease in patients with rheumatoid arthritis. One of the factors not considered in this study is the severity of the autoimmune disease or genetic factors predisposing to autoimmune disease which might make a patient more likely to develop CNS inflammation.

FROM THE PARKINSON'S DISEASE RESEARCH REVIEW

Read more at: researchreview.com.au

Dementia and subthalamic deep brain stimulation in Parkinson's disease (PD), Bove F et al. (Issue 42, 2020)

Dementia following bilateral STN-DBS was evaluated retrospectively in 175 patients with PD; 104 had follow-up data out to 10 years. Risk factors for dementia after STN-DBS were male sex, higher age, hallucinations, lower frontal baseline score and perioperative cerebral haemorrhage.

Comment: The literature has been conflicting, but some studies have suggested a negative impact of STN-DBS on cognition, and dementia has been considered an exclusion criterion for DBS for this reason. This longitudinal study reviewed 104 PD patients, treated with STN-DBS, over 10 years. The risk

of dementia was 26% after 10 years; and the incidence rate of dementia was lower than reported in other longitudinal studies of PD patients without DBS. Although direct comparison is difficult because of the differing mean ages of the cohorts; the data provided some useful statistics for counselling patients considering DBS.

FROM THE MULTIPLE SCLEROSIS RESEARCH REVIEW

Read more at: researchreview.com.au

Use of natural medicine and dietary supplements concomitant with conventional medicine among people with multiple sclerosis, Bergien SO, et al. (Issue 49, 2020)

The use of evidence-based MS therapies with conventional and alternative medicines (CAMs) is common, and natural medicine and dietary supplements (NADS) are the most frequently used. Research is important because of the potential for interactions with conventional treatments.

This Danish phone survey of 384 MS patients, confirmed that 85% have used at least one CAM within the last 12 months. Even when excluding vitamin D, 78% of patients used agents including fatty acids, multivitamins, and calcium.

HERE WE PROVIDE SOME SUMMARIES OF RESEARCH SOURCED FROM WEBSITES IN AUSTRALIA AND AROUND THE WORLD: WE HOPE IT'S OF INTEREST TO YOU.

WE HAVE INCLUDED BOTH MS SPECIFIC AND OTHER NEUROLOGICAL RESEARCH UPDATES.

READ MORE AT MSWA.ORG.AU/RESEARCHUPDATE

The most common reason for using CAMs was to "strengthen the body" followed by "because it was recommended".

Conclusion: The study contributes to a better understanding of NADS used among PwMS and shows that the majority of PwMS use NADS and that they use it as well as the conventional MS medicine. Furthermore, the detailed mapping of the specific types of NADS used gives a nuanced insight into the specific products of NADS used among PwMS, including different kinds of vitamins, minerals, and herbal remedies.

FROM MS RESEARCH AUSTRALIA

Read more at: msra.org.au

MS Risk Increasingly Affecting Women. Why?

An international group of leading women in MS, including clinicians and researchers, has compiled an extensive review of the sex effects throughout their lives on MS.

Recent studies suggest that MS cases are increasing and that the increase is disproportionately affecting females. The female to male sex ratio of MS has risen in several countries in recent years, currently in Australia 75% of people diagnosed with MS are women.

Sex hormones play a significant role in the risk and course of MS. Dramatic hormonal fluctuations can influence clinical, radiographic, and disability-related disease parameters. The role of sex chromosomes on sex differences in MS risk and disease progression represents a new frontier for exploration.

More research is needed to fully understand unique questions relating to MS and fertility, contraception, pregnancy, and reproductive aging.

Positive News for Women with MS Planning Pregnancy

World renowned researchers combined results from previous studies of 7,034 pregnancies of 6,430 individual mothers, to provide an updated picture of the effects of pregnancy on MS.

They confirmed the historic assumption that pregnancy reduces MS relapses, although there is a slight disease 'rebound' after birth. Pregnant women on modern MS treatments are significantly protected from relapses compared to those in earlier decades.

There were misconceptions in the past about the effects of pregnancy on MS, and some MS medications are unsafe for pregnancy, requiring careful decisions around optimising safety for mother and baby. Combined with the uncertainty MS brings, there can be significant anxiety for women with MS around having children.

Two world renowned British scientists teamed up with Australian Dr Vilija Jokubaitis to investigate the effects of pregnancy on the number of relapses at different stages of pregnancy and immediately after childbirth. They combined results from 28 studies that met robust quality criteria: from 1998 to 2019.

Findings: Choosing to start a family is a momentous decision and carries additional considerations for women with MS. This study confirms that pregnancy can reduce relapses, and that control of MS, including for pregnant women, has improved significantly in the last two decades.

The study highlights the importance of close communication and planning between a new mother and her neurologist when planning a pregnancy, as some disease modifying therapies are unsafe during pregnancy and to ensure tailored treatment in the period immediately after childbirth.



FROM THE MS SOCIETY OF CANADA

Read more at: mssociety.ca

New health conditions identified as part of the MS prodrome

Neurodegenerative diseases such as Alzheimer's and Parkinson's, can start years before clinical diagnosis and are often preceded by a range of health issues. Individuals with Parkinson's may experience depression and constipation years before the classic symptoms, such as motor deficiencies, are detected. These early symptoms are collectively known as the 'prodrome'.

Recent evidence suggests the existence of an MS prodrome, as reported by Dr Helen Tremlett's research team at the University of British Columbia. They found that in the five years leading to the onset of MS-related symptoms, people diagnosed with MS were up to four times more likely to visit a physician or hospital for conditions related to nervous system disorders. Higher rates of other health issues, including musculoskeletal pain, mood or anxiety disorders, and migraine headaches, were also observed among MS cases. Recognising the earliest signs of MS years before the development of classic symptoms could be important for early disease detection and intervention. Thus, additional research is needed.

The study reviewed clinical data from British Columbia and records of nearly 8,000 individuals with MS and more than 35,000 without MS (controls). The most prevalent conditions among MS cases in the preceding five-year period before onset of classic symptoms (eg, first demyelinating event) was pain, followed by sleep disorders, anaemia, and fatigue. The odds of having a sleep disorder were up to 161% higher in MS cases compared to controls, and the odds of experiencing pain were up to 115% higher.

FROM THE MS TRUST UK

Read more at: mstrust.org.uk

Myelin Repair Research

Repairing the damage to nerves caused by MS is possible, according to new research.

A study of the cancer drug bexarotene in Cambridge and Edinburgh showed it led to regrowth of myelin in people with RRMS. However, the dose needed to produce this effect led to serious side effects including thyroid disease and potentially damaging levels of blood fats.

Whilst the fact it is possible to encourage the regrowth of myelin in humans is a breakthrough and will lead to further research, the side effects mean that bexarotene will not become a treatment for MS.

The Cambridge team are planning another remyelination study using metformin (a diabetes drug) in combination with clemastine (a treatment for hay fever and allergies).

FROM MULTIPLE SCLEROSIS News Today

Read more at:
multiplesclerosisnewstoday.com

Pathway and Its Proteins Found to Control Myelin Repair, Renewal.

Researchers have identified a pathway controlled by three proteins — Daam2, Nedd4, and VHL — as a key regulator of myelin production during central nervous system development and regeneration after injury. Myelin, the protective fatty layer that covers nerve fibers and helps to speed transmission of signals between nerve cells, is damaged and lost in MS.

Iron Deficiency May Be Linked to Depression and Poorer Life Quality.

A small Polish study reported that low blood levels of ferritin — the main form of iron stored in cells — are significantly associated with more severe depressive symptoms and poorer quality of life in MS patients. Data showed no link between the levels of other measures of iron metabolism and fatigue severity.

\$10.5M NATION-WIDE COMMITMENT TO MS RESEARCH

Each year MSWA is able to continue our commitment to neurological research locally, across Australia and worldwide. By funding a variety of projects through different institutions, we hope to continue to make real differences for real people living with a neurological condition in WA.

As part of last year's financial allocation, we contributed \$2.1m to MS Research Australia (MSRA) to form part of their \$10.5m national boost towards multiple sclerosis research.

MSWA is proud to support MSRA's movements towards finding ground-breaking research results.

"This record figure, formed nationally, shows Australia's commitment to finding new treatments for MS. Funding efforts will significantly enhance research outcomes in Australia as well as fast forward the process for identifying effective MS treatments." – Marcus Stafford, CEO.

For more information, visit MSRA's website: msra.org.au/news/record-funding-for-ms-research/

RESEARCH IN FOCUS

Here, we provide an insight into the research projects we are funding in Western Australia.

DEMYSTIFYING DEMYELINATING DISEASES

MSWA is proud to continue funding the Perron Institute's Demyelinating Diseases Research group, led by group Director and Clinical Professor Allan Kermode.

Since our last update the group has been active across many areas in 2020, despite the disruptions caused by COVID-19, with members working both independently and collaboratively towards shared targets.

In the first seven months of 2020, the group published 12 peerreviewed papers and a further 12 have been submitted or accepted for publication.

Dr Marzena Fabis-Pedrini, a key member of the group, is an MSWA Research Fellow at the Perron Institute. She is leading research into biomarkers, including neurofilament light chain, to personalise treatment options for people living with multiple sclerosis.

Dr Fabis-Pedrini is also leading studies into the use of quantitative assessment management of MS, and the interrelated effects of environment and immunogenetics. Collaborations established have been with Sun Yat-sen University the Chinese University of Hona Kong, and University of California, San Francisco USA to leverage these findings.



Clinical Professor Allan Kermode – Consultant Neurologist and Head of the Demyelinating Diseases Research at the Perron Institute.

Also with funding from MSWA, Dr Stephanie Trend, an MSWA Research Fellow with the Perron Institute based at the Telethon Kids Institute (TKI), has continued work with the group on a long-term collaborative project led by Professor Kermode and Professor Prue Hart (TKI). The research has been evaluating the effects of UVB phototherapy as a potential new intervention for people diagnosed with clinically isolated syndrome (single episode) in early MS.

Gathering pilot data pivotal generated with MSWA support by Professor Hart's team, has enabled chief investigator Dr Trend and her team to be awarded a nationally competitive MSRA project grant, which is investigating the role of antibodies and B-cells in MS. This recent work has benefitted from a new collaboration with Professors Björn Frendéus and Ingrid Teige and their colleagues at BioInvent in Sweden.

Dr Xiaonan Zhong, neurologist and University of Western Australia PhD scholarship recipient, has also been busy studying T-cell immune targets in immediate post-mortem MS lesions in a collaboration with Murdoch University, the Erasmus Medical Centre Netherlands, and Vanderbilt University USA. The results will be pivotal in determining the key drivers for the development of the MS lesion.

While the work being conducted by each researcher is diverse, it is all scientifically related, with topics strategically designed to interlink.

For more information about MSWA funded research, head to our website: mswa.org.au/news-research/research

INDEPENDENCE DAY

A recent announcement by the NDIA has raised questions as to the Scheme's ongoing pursuit of a personalised approach to disability services.

From its inception, one of the driving factors of the National Disability Insurance Scheme (NDIS) was the installation of a model that reflected individuals, not conditions. The person-centred approach to funding transformed the disability sector and was an important step towards empowering individuals to achieve their goals in a supported, personalised way.

However, recent changes to the Scheme have raised concerns that this personalised approach may be changing as the government announced new independent assessors will be installed from 2021 as part of their response to the recent 'Tune Review'.

Which raises three important questions:

- 1) what's a Tune Review?
- 2) what's an independent assessor?
- 3) what does it mean for you?

The Tune Review was a review into the NDIA by David Tune, a former senior public servant. His 2019 report is the basis for the Government's new Participant Service Guarantee and has 29 key recommendations to cut delays, reduce complexity and improve services. So far so good.

More good news was that one of the recommendations was a review into what 'reasonable and necessary' means as this can be confusing for participants and providers alike. To solve this problem the NDIS announced in September that it would be installing 'independent assessors' to undertake functional capacity assessments that support NDIS access, planning and reviews. Unfortunately, this is where I start to get some concerns.

While participants currently receive reports of the participant's choice from allied health professionals who have spent time with the Customer and understand their particular situation, it is proposed that these new assessments would be conducted by NDIS-appointed healthcare professionals (fully paid for by the NDIS) using standardised tools. And that's the word that gets me concerned – standardised.

To be fair to the NDIA, much of what 'independent assessment' looks like is still unknown. However. according to reports, assessors will complete a '20-minute (minimum) interaction or observation session' with the participant before writing their report. So the basis for your entrance to the NDIS or review of your changing needs could be based on a short 20-minute conversation. Also, this is a good time to point out that the NDIS has been conducting their planning sessions by phone since COVID-19 so, likely, these conversations may not be face-to-face or in the home.



Of further concern is that it has been stated that "Assessors must not provide Participants or Prospective Participants with copies of the Assessment Reports or discuss results or outcomes with Participants or Prospective Participants in any way." So, if you want to discuss the outcome of the report and supply further information to change the outcome you may not get the chance.

Again, I must stress that we do not know the full scope of what these roles will look like. However, this announcement has raised some concerns and without pre-judging the result, is an issue that should be monitored over the coming weeks.

GEOFF HUTCHINSON MANAGER CUSTOMER ENGAGEMENT

SUPPORT COORDINATION HELPING YOU NAVIGATE YOUR NDIS PLAN

At MSWA we recognise that navigating the NDIS can be complicated and challenging. Finding and choosing your provider can be overwhelming and time consuming. Some people may prefer to manage their NDIS plan themselves. Others feel that they require support to understand and navigate the NDIS and its process. This is where Support Coordination can help you.

WHAT IS SUPPORT COORDINATION?

Support Coordination is a funded service within your NDIS plan. The purpose of this support is to help you build the skills that you need to understand and implement your NDIS plan. Support Coordination provides ongoing assistance to help you connect to appropriate services and supports, as outlined in your NDIS plan, and helps you coordinate these supports.

CUSTOMER EXPERIENCES

Claire Suter

"I am reaching out to those of you who are having a hard time navigating your NDIS plan, or formulating them for the first, second, or even third time. My advice is to speak to MSWA about getting a proactive and approachable Support Coordinator who is passionate about their role and empathetic to your situation.

When you are finding life hard and you are unable to find the muster or inclination to put your point across or to take care of yourself, and lacking in self-confidence, your MSWA Support Coordinator will be an excellent advocate. Your coordinator will attend meetings with service providers, attend your home when discussing home modifications, and assist with any situation where you might need moral support.

I cannot speak highly enough of my MSWA Support Coordinator, Kath. Having an individual who takes an interest in me has made such a difference to my daily living.



MSWA Social Welfare team.

Nothing appears to be too much trouble. She anticipates my NDIS needs and is both an advocate and fountain of all knowledge.

My final advice is to be prepared to meet your coordinator halfway by, for example, reading the material you receive in the mail and online from either NDIS or service providers. This will help you raise questions and make choices. It should be a collaborative effort."

Claire Kennelly

"Hello, let me introduce myself. I am Claire and I have multiple sclerosis. Prior to January this year, my symptoms were pretty much controlled, and I enjoyed MSWA and all that was offered, including the bonding with others affected by MS. Then, I had a relapse which was a game changer. I felt I had nobody to help me with this 'new normal'.

MSWA came in when nobody else was looking after my health. My MSWA Support Coordinator, Wayne, was one of the main reasons I never gave up on a situation which seemed hopeless. Wayne organised all my supports – care support workers, physio, counselling and welfare services. Wayne visited my home and helped me navigate to get all the care I needed. He also supported me in processing my claims for NDIS, which I really had trouble with.

I am recovering little by little which is easy when you have strong support – which for me comes from MSWA and the guidance and help from my 'church family' at The Grove Church.

It was because of them all, collectively, that I didn't give up. After all, MS is just a shortened form of Mighty Strong."

If you need Support Coordination and currently do not have this funding in your NDIS plan but have funding under Core Budget, there is good news. The Core Budget can now be used flexibly to cover your Support Coordination needs.

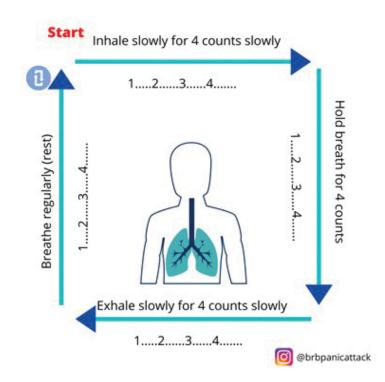
To find out more about Support Coordination at MSWA, please contact the Social Welfare team on 9365 4888.



I was always a little amused in my yoga/meditation classes by the instruction to take in the breath, curiously follow the breath into the body and then slowly exhale the breath. I would often find my mind wondering about 'this breath' and how this breath is any different to the one I take unconsciously at any other time of the day.

When I began to connect the breath to every muscle and fibre of my body for nourishing and oxygenating the blood, I began to focus not only on the breath, but how my body responded. Research now shows that under-utilising the body when breathing may lead to imbalances within the body! Why would a counsellor be interested in the breathwork for therapeutic work?

Breathing can be a tool used to help relax the body, reduce stress, provide a better way to regulate the body's reaction to fatigue, managing pain and harvesting emotional wellbeing². Research also shows that focusing on breath work can help provide the brain with an increase in oxygen for increased cognitive function and balance³.



There are many breathing apps available today to promote breathwork, such as *Calm, Insight Timer,* and *Breathe+*.

It is important to find what suits you. One exercise that I like to follow is the visualisation of a square (see diagram).

¹ Fried, R. 1990. The Breath Connection.

 $^{^{\}rm 2}$ A, Weil. 1999. Breathing; The Master Key to Self-Healing.

³ Morningstar, J. 2017 Break Through with Breathwork.

EXERCISE PHYSIOLOGY AT MSWA

Please allow me to introduce myself. My name is Luke and I'm an Accredited Exercise Physiologist (AEP) who recently joined MSWA's Physiotherapy team. I will be servicing the Rockingham and Mandurah regions, both in-clinic as well as providing home visit exercise therapy sessions to Customers in the area.

I am one of a small but growing number of AEPs working in the Physiotherapy team at MSWA. Exercise physiology is an emerging allied health field of university-trained healthcare professionals, specialising in clinical exercise interventions for people with a broad range of health conditions.

AEPs are trained extensively in the benefits exercise has on the human body, both mentally and physically, and equipped with the knowledge and skills to design and deliver safe and effective therapeutic exercise interventions for people with acute and chronic medical conditions, injuries, or disabilities. AEPs are specifically trained with a focus on the management of chronic conditions, with an emphasis on increasing functional capacities and quality of life.

AEPs work with people who may be affected by a number of conditions, including heart disease, COPD, cancer, diabetes, post-operative rehab, chronic pain, mental health, and, of course, neurological conditions like MS, Parkinson's, Huntington's, MND, and others.



Luke Everett, Accredited Exercise Physiologist, with MSWA Customer, Charles Van Niekerk.

At MSWA, AEPs work alongside our physiotherapists to provide our Customers with ongoing therapy specifically tailored to each individual. Regular exercise offers many benefits for people living with neurological conditions, including improving strength, balance, endurance, and cardiovascular health, as well as reducing fatigue, stress and anxiety.

LUKE EVERETT ACCREDITED EXERCISE PHYSIOLOGIST



Brett and Kylie Jones' phone rang early. "Who on earth is calling at 7:45?!" said Brett.

It was Friday, 11 September 2020, and on the other end of the call was Marcus Stafford, MSWA CEO, telling Brett and Kylie they had won the \$3.5 million Grand Prize in the MSWA Mega Home Lottery.

In a first for the MSWA Mega Home Lottery, the winning couple are not only long-term fundraising supporters, they are also MSWA Customers.

As the prize draw is independently audited and drawn through a certified random number generator, Marcus did not know who he was calling that morning, and was gobsmacked when Brett identified himself – the couple had met Marcus on a few occasions at their local MSWA Services Centre in Beechboro.

"Big fella, is that you?" exclaimed Marcus. "Well, that's just made my day!"

When the call ended, the couple sat just sat staring at each other.

"I was sobbing," recalls Kylie.

They rushed to tell Brett's parents, who live next door: "WE'VE WON THE HOUSE!"

It was a truly life-changing day for Kylie and Brett. Over the years, the pair have battled through money worries, MS-related curveballs, and Brett has had several heart attacks after an accident tore a valve in his heart.

"My children have seen me cry twice," says Brett. "Once, when my nana died. And the day we won the Mega Home Lottery."

Kylie was diagnosed with multiple sclerosis (MS) in 1998, aged 32. By 2001, Kylie's mobility and spatial awareness were significantly affected, so Brett quit his job as a butcher to care for Kylie full-time.

"I chose to leave work and look after Kylie," says Brett. "I love her. We signed up to do everything together."

The initial diagnosis was a shock – neither of them knew much about life with MS. Kylie presumed the worst and, on a low day, told Brett he should leave her.

"I laughed and said to her, 'Where else would I want to go?!" recalls Brett. This was around the time of their 10year wedding anniversary. Wanting to make a meaningful gesture, Brett organised a party and secretly arranged for the celebrant who married them to attend and renew their yows.

"It was wonderful," says Kylie.

This story sums up the couple's attitude to life.

"We've always tried to stay happy," says Brett. "Sometimes it's been harder than others."

Kylie says she focuses on being positive for Brett, their three daughters and five granddaughters. "If Mum stays happy, everyone is happy," explains Kylie.

Kylie and Brett have been supporting the MSWA Mega Home Lottery for many years.

"The cause is so close to our hearts. We always try to buy two tickets," says Brett. Ironically, they only purchased one ticket in the draw that they won because their budget couldn't stretch to two this year.

The couple regularly attend the MSWA Beechboro Services Centre for the Outreach group and physiotherapy for Kylie.

"Without the Centre, people would really struggle," said Brett. "The staff are fantastic. Some people don't have partners and MSWA is where they go to get support. Not every Kylie has a Brett."

Like many people who are newly diagnosed, when first joining MSWA in 1999, Kylie was hesitant about attending Outreach.

"I didn't want to see my future," she says. "What I didn't realise was that MS affects everyone so differently. Once I worked up the courage to go to Outreach and saw people at all stages of their condition – walkers, wheelchairs, sticks—I thought, 'There's not one of us that is the same'. We've been attending ever since."

Kylie and Brett are proud that their children and grandchildren often attend Outreach with them, noting that Kylie's condition has complicated the kids' lives but that they are richer people for it.

Once, after a visit to the Beechboro Services Centre, Brett's young granddaughter was trying to describe an Outreach attendee to him, saying "he was the man in the green jumper". Brett was taken aback, realising that "the man in the green jumper" was also the only person there using a wheelchair – but that's not what his granddaughter noticed about him. She didn't see the disability. Brett recalls it as one of his proudest moments.

"At Outreach, everyone is so different, but we all have the one thing in common," says Kylie. "You walk in those sliding doors and everyone is equal."







Top: Brett and Kylie celebrating with MSWA Beechboro staff.

Above: Photos from Brett and Kylie's blog: on the road in the MS-friendly motorhome they converted.

The couple's youngest daughter, Rebecca, says, "The most positive thing about your mum having a neurological condition is witnessing all the challenges she's overcome. Mum and dad have the most positive outlook on life. They're a massive inspiration, my parents. Everything I've ever done it's because of these two."

Kylie and Brett attribute a large part of their happiness to taking regular trips around Australia in a van they converted into an MS-friendly motorhome, installing handrails anywhere Kylie needs them.

They document their travels on a Facebook blog titled 'Our Adventures – On the Road with MS' with the aim of inspiring other people to get up and go on an Aussie adventure, no matter your budget or ability.

"We've always had a small budget so we stay in free campsites in the bush or in the yards of the amazing people we've met on our travels. We love it." says Brett. "When we were trying to process the news about winning the Mega Home Lottery, Kylie said to me 'You know, we can probably afford to stay in some caravan parks now'.

"It's the funniest thing I think I've heard!"

"I can't see us doing that," remarks Kylie.

"Yeah, we probably won't!" laughs Brett.

In seriousness, Brett adds, "My biggest stress has always been 'If something happens to me, how will everyone take care of Kylie?' Now I don't have to worry."

Brett muses, "We've done the sickness, we've done the health, we've done the poor. Now we're doing the rich."

VISITING NARELLE

Many of you will remember Narelle Taylor well. Up until nearly a year ago she published articles in *Bulletin* magazine. Narelle is a close friend of mine and is also an inspiration to me.

I always used to open *Bulletin* when it arrived in the mail and eagerly turn to Narelle's article so I could read it first. I always thoroughly enjoyed them, and when I started writing articles myself, I admit that there are elements of her style that I copied. I enjoyed the combination of humour and poignancy with which she described her life, living with multiple sclerosis.

Narelle lives in an aged care facility now. I visit her regularly and I can assure you she has lost none of her quick wit or her sharp intelligence. I can also mention that she usually has a bottle of wine or two in the little bar fridge in her room, and some glasses on a shelf in her wardrobe, and she loves to have a conversation over a glass or two.

During 2020, the COVID-19 situation put some limitations on Narelle that meant she appreciated my visits even more. I often took my friend David along with me, and he has come to love her as much as I do. During our visits, Narelle has shared much about her early life with us and has delighted us with her reminiscing.

Narelle grew up and went to school in Sydney. She married Greg Taylor in Kalgoorlie in 1974 and had three delightful girls. She and her family moved to Arnhem Land in 1977, where their third child was born in 1981. Narelle taught literacy and numeracy to Indigenous people while she was there. In 1982 they built and launched a boat, on which they travelled in the northern parts of Australia and lived for three years.

I can't imagine travelling with little toddlers and babies on a boat, but Narelle did it and everyone survived to tell the tale!

Back on land, Narelle managed the Geraldton Tourist Bureau for a while, then lived in Leinster where she and her husband managed their own business. She was diagnosed with multiple sclerosis in 1992, and moved to Perth a couple of years later, where Greg started an engineering business. The girls went to school and university in Perth, and they are now all married and Narelle enjoys her five grandchildren very much. Sadly, her husband Greg died unexpectedly and suddenly in 2018.

This year, COVID-19 has meant that for a while, visits to Narelle's facility were limited but with the right preparation we could still go. We had to provide proof from our doctors that we had had flu vaccinations, and on entry our temperatures were taken. There were some limitations initially about when we could visit, and how long we could stay. These restrictions also applied to Narelle's daughters and grandchildren, so the number of visitors she had was much reduced. Narelle remained in communication with me via the computer, and I know she was feeling quite lonely for some months. Previously she had often made her way in her electric chair to a nearby café where she would enjoy a cup of tea and cake with friends, but for several months that was not allowed either.



If you have a friend or relative who lives alone or in a facility, make the effort to visit them as often as you can. David and I love our visits to Narelle, and always come home happy. Not only will you bring joy into someone else's life, you will bring joy into your own.

ROS HARMAN GUEST EDITOR





"We met at a dance, like everyone in those days," recalls Anita Terranova.

Anita is speaking of her husband, Joe, who was born in Sicily and came to Western Australia in 1956, aged 23. The pair have now been married for 57 years.

It was 1954 when Anita, who was training to be a model, lost balance and tripped over the end of the catwalk during a photoshoot for a Kalgoorlie newspaper feature (pictured right). This was the beginning of her journey with MS.

Anita recalls that little was known about MS back then and it took a long time to be diagnosed by her physician at Royal Perth Hospital, Dr Thorburn.

In 1963, shortly before Anita and Joe were married, there was an episode when she was paralysed for five months. She recovered and her condition remained largely dormant for many years.

"I had a good specialist," recalls Anita. "I was in bed for several months but he refused to visit me at home. He insisted, 'I'm not coming to you. You're going to get up and come and see me in my office.' And eventually I did."

At the time, the advice for women with MS was 'no babies'. However, 11 months after they married, baby Phil was born. Even though the birth went well, the couple were told it wasn't safe for Anita to try again. This advice has long since changed; motherhood is generally not discouraged as it was in the past when there were no or few treatments and little supporting evidence. Today a neurologist will evaluate the individual risks to the patient regarding pausing treatment, pregnancy, delivery and potential post-partum relapse of MS symptoms.

Anita recalls that baby Phil helped to keep her distracted.

"When you rear your child, you give it the best you can. The child helps you. You can't think about yourself. I had to be there for him."

Joe was running a successful butchery business in Northbridge, a profession he retired from 10 years ago. He has always been an active and valued community member, particularly within the Italian community in Perth.

Joe and Anita are now aged 88 and 86, respectively. The pair are grateful that Anita's condition progressed like it did.

"I must say this. I've been very lucky. I've had a lot of remissions," explains Anita.

In old age, however, both Anita and Joe have faced challenges with their health.

Joe has ongoing heart issues after suffering a heart attack in 1990. A few years ago, his heart stopped for three minutes, an experience that gave Anita quite a fright. He now has a pacemaker device which sets his heart rhythm and connects to a satellite.

They still live in their Yokine home together and Joe explains, "Until I can't stand up and move myself, she stays with me."

Joe is an excellent cook, but the couple need extra help at home which they access via a Home Care Package with MSWA. Home Care staff, who are all trained with an understanding of neurological conditions, visit them at home to help with house cleaning, weekly grocery shopping and assistance for Anita to shower and dress.

Joe also benefits from a weekly respite service with MSWA which enables him to have a break from his caring role and allows him to maintain his social connections. They also receive monthly gardening services as well as podiatry, physiotherapy and counselling services within their own home as part of their Home Care Package with MSWA.

"We've had a good life," says Anita. "But the older you get, the less you can cope."

After six decades of living with MS, Anita reflects that it's difficult to explain MS to anyone.

"Every morning you wake up different from when you went to bed. It lets you know each day what you can do.

"I've been living with MS for 66 years and my advice to others is that you've got to be strong. This isn't a disease you give up on – you need to tell yourself this isn't going to beat me.

"I was a model until I tripped over the end of the catwalk. But in the end, I had a beautiful future to look forward to. My advice is to live every day. You never know what the future is going to hold. If you want to do something, do it."



MSWA HOME CARE PACKAGES

MSWA is now an approved provider of Home Care Packages, a government initiative helping older Australians access affordable care services to remain living at home safely and independently.

MSWA can deliver all levels of Home Care Packages to eligible people with a neurological condition who are over 65 (or over 50 for Aboriginal and Torres Strait Islander peoples).

Already receiving a Home Care Package from another provider? Speak to us about switching over to a neurological specialist.

Looking to apply to My Aged Care for a Home Care Package? MSWA can help you with the process.

Speak to our Aged Care Coordinator on 08 9365 4888 or email aged.care@mswa.org.au.



More than ever, it is important to take care of our mental health. Our brains are wired to focus on threat and the regular practice of mindfulness can deactivate the emotional centre of the brain, resulting in peace and calm.

Mindfulness is simply paying attention, moment by moment, on purpose and non-judgmentally to our experience as it is.

Mindfulness of thoughts.

This practise uses the skill of 'detachment' where we become aware of our thoughts, noticing, but not engaging in them. As our awareness increases, we notice when our thinking gets 'hooked', when we are overthinking or if we are critical of ourselves. This awareness can direct us to 'unhook' and turn our attention to a more helpful focus.

Mindfulness of the senses.

This practise directs us to 'focus' on our breath or one of our senses. Focusing on our senses while we are mindfully eating or mindfully walking is a core relaxation exercise.

While waiting in a queue, take a deep breath, focusing on the breath entering and leaving the body. Observe something you can see, maybe the detail in a picture. Notice one thing you can hear, perhaps the sound of birds. Notice something you can feel, for instance the texture of clothing. This practise of 'focusing' is particularly helpful when overwhelmed with anxiety or panic.

Another core mindfulness practise is 'focusing' on progressive muscle relaxation.

Mindfulness of the emotions.

Our impulse when we have a strong emotion is to suppress it. Mindfulness encourages us to befriend our emotions, taking a more curious stance of how an emotion might feel energetically and physically in our body. We can allow emotions like stormy weather to form and then dissipate, staying with the calmness of the blue sky.

Mindfulness as a circuit breaker.

If our brain has been habitually on overdrive due to prolonged chronic stress, mindfulness can be used as a circuit breaker by encouraging us to breathe slower and more deeply, relaxing your jaw area and tongue. Imagining increased warmth in our hands can lower our heart rate, blood pressure and stress hormones.

Mindfulness as compassion.

Paying attention to yourselves and others in a non-judgmental way is one of the kindest things we can do. In these times, kindness is perhaps what we need the most.

Further reading:

palousemindfulness.com

perthmeditationcentre.com.au

self-compassion.org

The Things You Can Only See When You Slow Down by Haenim Sunim (book)

marshalucasphd.com

TAKING A BREAK IN OUR RESPITE HOMES

MSWA has two wonderful Respite facilities, one at City Beach (five bedrooms) and one at Australind (six bedrooms), where our trained and caring staff can provide 24/7 care and support for our Customers living with a disability.

Take the opportunity to have a break from your in-home schedule and/or give your carer some well-deserved downtime.

If you would like more information about the facilities, how to book and what to expect, please call (in office hours):

- / 9385 9574 for Margaret Doody House (City Beach) and ask for the Manager, Alimul Tasin
- / 9725 9209 for Treendale Gardens (Australind) and ask for Linda Kidd or Paula Kennedy

Many of our Customers have funding allocated in their plans (NDIS or CoS) to cover their stay. Chat with our friendly staff about how your stay could be funded.

Christmas closure: Both homes will closed for a couple of weeks over the Christmas break, when demand is negligible. Please contact the Managers on the details provided regarding all booking enquiries.

SUE SHAPLAND RN, BN, MSCN GENERAL MANAGER STRATEGIC SUPPORTS AND RESIDENTIAL OPTIONS



THE AUSTRALIAN MS LONGITUDINAL STUDY (AMSLS) IS LOOKING FOR PARTICIPANTS.

AMSLS is a survey-based research study designed to provide a comprehensive picture of all Australians living with MS. The study aims to enhance our understanding of MS, which helps provide better services and support for people living with MS.

Whether it's the journey to diagnosis, lifestyle factors used to help manage symptoms, or stories of workplace experiences, every one of the 25,000 people diagnosed with MS in Australia has a unique and important journey to share.

No matter where you are in your journey or the impact MS has on you, all insights are valuable.

The Study is a partnership between MS Research Australia and the Menzies Institute for Medical Research (University of Tasmania). They encourage all Australians with MS over 18 years of age to register with the Study and share their story.

The AMSLS consists of 2 or 3 short surveys, taking just a few hours each year, which can be completed in the comfort of your own home, at your own pace.

If you would like to get involved, please visit msra.org.au/AMSLS







MSWA Camps are back! And what a program we have.

Hello, and let me introduce myself to those who don't know me. I am Dawn Burke, Camp Coordinator. I have been working for MSWA as a Volunteer Coordinator for nine years and have been privileged to attend many camps since I started here. Until recently, I supported our lovely Sumit, the previous Camp Coordinator, who has spread his wings and left the nest. For those of you asking after Sumit, he is doing well and misses you all, and I have taken over the reins.

Once some COVID restrictions lifted, it was pedal to the metal organising some much-needed, if slightly different getaways, for our Members, their families, and carers.

The MSWA camps are funded through Lotterywest. We attended two camps in September, and two Carer Retreats and a South West Members' camp in the weeks that followed.

A few Members recently enjoyed a stay at our Treendale Gardens Respite facility, in Australind. The group was smaller than usual but just as much fun. It was a safe way to reintroduce camps with limited numbers and a great opportunity for them to see what Treendale is all about should they need respite in the future to provide relief to family or a break from routine. Treendale is such a beautiful facility and the staff were definitely 'all hands on deck'. Treendale usually takes six guests at once, but we stretched them to nine by utilising the adjoining family holiday unit.

I would like to say a huge thank you to the support staff, coordinator, and management, for stepping up to the challenge and making this work for our Customers, it was truly appreciated.

One of the camp activities organised was a visit from the local FESA station. They discussed safety in the home and ideas on how to be fire smart and keep yourself safe. We checked out their fire engines, which had amazing Aboriginal artwork on the side panels. It certainly was a great way to spend the morning.



The second camp was our annual Family Camp at the Woodman Point Department of Recreation site. We had great numbers with 16 children and 15 adults. There was so much going on around the place and the kids clicked together straight away. It was lovely to see some families returning and to have new families attend, experience holidaying together, and take part in activities they ordinarily may not have the opportunity to.

This year we were exceptionally lucky to have some of our activities funded through money raised directly by Western Australian participants in the MS Readathon. The kids had so much fun. To be honest, so did the adults. We went on the much-loved flying fox, climbed the rock wall, shot arrows in the archery field, and spent a few hours playing at the beach (pictured). After dinner, the volunteers took the children out to play 'spotlight', always a favourite for the kids. Darkness and a torch, what more do they need?



Family Camps are for parents and their children, from kindy through to Year 6. If you have a child in this age range, why not call and have a chat? Your other children are welcome, as long as one of them fits the above criteria. Parents are ultimately responsible for their children and MSWA will provide the activities, food, and accommodation.

What a great way to spend three nights away with your family, get to know other parents living with MS and for your children to know they aren't on their own on this MS journey.

The following dates have so far been secured for early next year.

Carers Retreat, Monday, 15 March 2021 – Rottnest Island

Members Camp, Monday, 12 April 2021 – Woodman Point Recreation Centre

For anyone interested in attending a camp, please contact me on 9365 4843 or dawn.burke@mswa.org.au.

I look forward to seeing you at our next camp experience.

MEDICATION UPDATE

Australian Government approves PBS listing of Siponimod (Mayzent®) for secondary progressive MS

On 25 October 2020, the Federal Health Minister, the Hon Greg Hunt MP, announced the listing of siponimod (Mayzent) for the treatment of secondary progressive MS (SPMS) on the Pharmaceutical Benefits Scheme (PBS), from 1 November 2020.

The Pharmaceutical Benefits Advisory Committee (PBAC) recommended the listing of siponimod (Mayzent®) for patients with SPMS who are ambulant (with or without support).

This PBS listing was recommended by the independent expert PBAC and is the first time in Australia that a medicine has been listed on the PBS specifically for the treatment of SPMS.

People living with SPMS should discuss any potential treatments with their neurologist or MS nurse.

Please consult your neurologist to see if siponimod (Mayzent®) is the right treatment for you. Decisions about treatments, taking into consideration the potential benefits and side effects for your individual circumstance, should be made in careful consultation with your treating healthcare team.

VOLUNTEER UPDATE

A big hello to you all! Since we last chatted MSWA's pace has picked up again, slowly to start with, and now we seem to be back to full steam ahead.

I would like to say an especially big warm welcome to our newest recruits, you are part of the big beautiful 'MSWA Family' now!

I have been very busy, as I have now taken on the added role of Camp Coordinator, which has kept me on my toes. The beauty of having both the Volunteer and Camp Coordinator roles is I get to see most of you a bit more often with the extra days in the office. It gives me great joy seeing so many of your smiling faces and catching up for a chat. I was extremely lucky to have four new volunteers attend the recent Family Camp, which makes all the difference, especially when we had 16 children in attendance.

Thursday, 5 November was International Volunteer Managers Day. This day celebrates the profession and the leadership that many provide to volunteers all over the world. The theme for this year is 'What's next?' Volunteering has seen many challenges due to COVID-19, and many lessons have been learned.

Not all volunteer managers and coordinators are as fortunate as me to have as many volunteers in place.

I am proud to be a Coordinator of Volunteers and I acknowledge you, and the people we serve. I would also like to acknowledge Trish Watson, as she coordinates all volunteers at our events. This is a massive job, and she does it so well. In November, our Events team held two fundraising and awareness campaigns - the Central Park Plunge (I take my hat off to those who participate by abseiling down Central Park) and the MSWA Ocean Ride, which is always a busy and long event for the team. Well done Trish and to all those who support vou!

A more significant day for volunteers is Saturday, 5 December. This is International Volunteers Day and the world's opportunity to spread its thanks across the oceans and to recognise volunteers for the difference they make to so many, no matter how small their contribution.



I would like to take this opportunity to thank each one of you for the difference you make to the staff and our Customers at MSWA. You are truly valued, appreciated and loved.

Lastly, on 14 October, the Wilson Outreach had Duo 41 come and sing to us. This was organised by our volunteer, Joan Crossman (pictured). Joan made this happen for one of our Members who has written two poems and she recited these poems with Duo 41 backing her up. It is little things like this that make a huge difference.

If you would like to discuss any volunteering opportunities or have a friend or two who may like to volunteer with us, please give them my details and we can have a chat. volunteer.coordinator@mswa.org.au or 9365 4843.

Take care, keep smiling and bye for now.



DAWN BURKE COORDINATOR -CAMPS AND VOLUNTEERS

DID YOU KNOW?

Did you know that you can participate in the MSWA Ocean Ride as part of your weekly physiotherapy routine?

Ros Harman, MSWA Customer, Board member and *Bulletin* guest editor, has been doing just that.

Ros attends physiotherapy at the MSWA Wilson Services Centre on a Monday morning and for the past eight weeks has been starting each session with a 15 – 20 minute stationary cycle to raise money for MSWA.

Ros uses a MOTOmed, a motorised movement trainer suitable for wheelchair users.

"It allows you to cycle yourself and then the machine takes over if you start to feel weak," explains Ros. "It gives you stats on how much you did actively, versus how much you did passively. I always try and do a little bit myself, around 0.2km per week."

The Stationary Cycle Challenge, as it's called, has no minimum distance requirement. Ros' goal is to ride 25km in total, which equates to about 4km each session.

This year, Ros set her fundraising goal at \$300, which she surpassed early on. Donors include a cousin in Oxford, England, who saw her post on social media.



Ros Harman and MSWA Physiotherapist, Kim Jahnig.

"The Stationary Cycle Challenge allows Customers to participate in the Ocean Ride and raise funds," says Ros. "I've been using MSWA services for 32 years now. It's great to be able to give back a little bit."

As well as the chance to fundraise, the Challenge is a chance to try a different type of physical therapy. Kim Jahnig, MSWA
Physiotherapist, explains,
"The MOTOmed is great to get
people's circulation going and
their joints moving. I've had
people come in who haven't
walked in years, and when they
try the MOTOmed they love it."

The Stationary Cycle Challenge is a cycling challenge completed on a stationary bike over an 8-week period, concluding the week of the MSWA Ocean Ride event.

There are prizes for the Highest Individual Fundraiser, 'Most Kilometres Ridden by an Individual' and 'Most Kilometres Ridden by a Team'.

For more information and to express interest in participating in next year's Challenge, you can contact your MSWA Physiotherapist, or get in touch with the MSWA Events team on 6454 3131 or email events@mswa.org.au

PROTECTING YOURSELF AND OTHERS FROM THE FLU AND COVID-19

This year's flu season has been quite different. Due to the hygiene precautions, lockdown and social distancing put in place in various measures due to COVID-19, the spread of flu has been vastly reduced this year. In 2019, Australia recorded 310,000 cases of flu, and whilst we are not quite finished with 2020, all indicators are pointing to significantly reduced cases.

The uptake of flu vaccinations this season has also been higher, helping to reduce the risk.

Thankfully, the community in general embraced the Health Department's recommended preventative hygiene measures to reduce the risk of spreading and contracting both the flu, and of course COVID-19.

TIPS TO REMEMBER.

/ Get your annual flu vaccination:

This doesn't cover you for COVID-19, but the flu vaccine will help reduce the risk of you getting both conditions and also lessen the strain on hospitals and your lungs — both seasonal influenza and COVID-19 can cause respiratory issues and even pneumonia, which can cause lingering problems. You don't want to get both at the same time.

/ Practice good hygiene

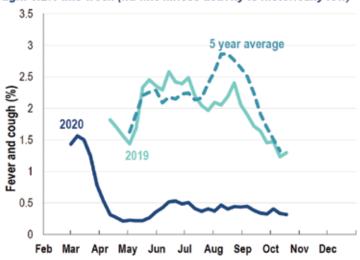
- · wash your hands frequently
- bin your used tissues, then wash your hands
- keep 2 metres between you and others
- · avoid sharing used dishes/towels
- · cover coughs and sneezes

/ Self-care at home

- social distancing
- get plenty of rest
- drink plenty of water and nonalcoholic drinks
- · keep warm
- · eat healthy foods
- · get plenty of fresh air
- · avoid exposure to cigarette smoke

Influenza-like illness activity:

Fever and cough: 0.2% this week (flu-like illness activity is historically low)



Source: FluTracking

Ifyou are unwell, seek medical advice, which may include a COVID-19 test, as we continue to monitor for potential community spread.

If you live alone, let someone know if you aren't feeling well so they can keep an eye on you.

You can generally treat the symptoms of a mild cold or flu at home and get better within 7-10 days without treatment. If necessary, your local pharmacist can assist with over the counter treatments.

See your doctor if you are experiencing high temperatures, headache, breathing difficulties, a rash, or if you are worried at all.

You can also speak to a registered nurse for free advice 24/7 by calling Health Direct on 1800 022 222. If you would like to speak to someone about the Coronavirus, please call the National Coronavirus Helpline 24/7 on 1800 020 080.

SUE SHAPLAND RN, BN, MSCN GENERAL MANAGER STRATEGIC SUPPORTS AND RESIDENTIAL OPTIONS



often with soap and water, or hand sanitiser



and sneezes with a tissue or use your inner elbow



from work if you are sick



SOCIAL DISTANCING
use
social distancing
of 2m



FEEDBACK AND COMPLAINTS

Feedback is vital; it helps us to understand what we are doing well, congratulate our staff on a job well done, and identify areas to which we can make improvements.

As a registered provider with the Department of Communities – Disability Services, the NDIS and Aged Care, MSWA welcomes your feedback.

In accordance with the National Disability and Aged Care Quality Standards, MSWA has a Complaints Management Procedure. This provides us with timelines to investigate and feedback the results with solutions for each complaint raised. We also provide de-identified reports to our funding bodies each year on the number and classification of the complaints received.

How do I provide a compliment, complaint or suggestion?

MSWA's Quality and Compliance Manager, Liz Stewart, coordinates the receipt of all formal complaints. She will chat to you about your feedback, explain the Complaints Management Procedure, review your concerns with the team involved and work to achieve a positive outcome.

To contact the Quality and Compliance Manager:

- / Telephone Liz Stewart on 6454 3173
- / Email feedback@mswa.org.au
- / Write to Quality and Compliance, Locked Bag 2, BENTLEY DC 6983

BEECHBORO OUTREACH

The doors for Beechboro Outreach reopened on Friday, 3 July 2020, following the closure during the pandemic. I am sure we were not alone in the celebration of this wonderful day. It was so amazing to see such a great number of Customers back through the doors.

We would like to extend a very warm welcome to Customers and staff alike, and thanks for their patience and cooperation in practising social distancing, hand hygiene and having their temperature taken every day since. As a result, everyone has remained safe and well and we have been able to get on with the real business of having fun!

In August, we had some great times with fun and games. Customers and staff each brought in a picture of their pet and we all had to try to match the pet to the person. It was all very hilarious as you can well imagine.

This year, the MSWA Home Lottery was an event even closer to our hearts, with a long-time Beechboro Outreach Customer and her partner winning the Grand Prize. It was amazing to be able to congratulate this lovely couple in person on their very well-deserved win.

The Father's Day barbecue was delicious as always with our amazing chef, Brenda, and two excellent door prizes were won by ladies who undoubtedly passed them on. Ladies, we hope you got you share of the goodies.

October saw us getting ready for a fun-filled and spooky Halloween. Customers joined in, helping us decorate Halloween ornaments, making strange but beautiful luminaries and exquisite Halloween posters. Customers had photos with the resident skeleton, 'Marcus', as named by the cheeky Michael Goodwin.

Eyeball guessing, mummy wrapping and door prizes for best dressed Halloween costume were among the many fun filled activities.

As always, miles of fun was had in the November Melbourne Cup Sweepstakes.

So again we would like to thank Customers, staff and volunteers for their ongoing commitment to the health and happiness of everyone at Beechboro and to extend warm wishes – for it will get warmer – for a safe and happy Christmas and New Year to you all, from the team at Beechboro Outreach.

CHRISTINE WESTON
RELIEF OUTREACH
COORDINATOR BEECHBORO



Halloween Craft: Suzanne Carver.

ALBANY OUTREACH

This has been a very odd year for everyone, and I hope you are all doing well.

We started this year with a guest speaker talking rubbish – more to the point – recycling. As the new 'coins for bottles' has started it was great to be reminded what you can recycle and what is rubbish.

There are a few locations where you can drop off your bottles (IGA Spencer Park, Stead Road and the foreshore). It will be interesting to hear how much is dropped off there and not on the side of the road.

Due to COVID-19, Outreach had a break for a couple of months but since being back we have had talks on Disability Advocacy and who you can contact if you are having issues with bullying, or you feel your rights have not been upheld. Also, Consumer Protection was discussed; scams are always a good topic and it was great to see that people are becoming savvy to scams, but there are still people getting caught, some losing many thousands of dollars.

The best speaker we had was Marcus Stafford, who in August gave an update as to where MSWA was at and how the new MSWA Albany Facility was delayed due to COVID-19. However, the success of the MSWA Mega Home Lottery, which was a sell out yet again, has meant the Facility has been given the go ahead to start ASAP. Very exciting news and we will keep you informed on what is happening when we know.

This year has gone so fast and it is getting closer to Christmas, so I wish you all the best for the rest of this year and hope to catch up soon.

CAROLINE CLARKE-SMITH OUTREACH COORDINATOR ALBANY

ROCKINGHAM OUTREACH

Rockingham Outreach is currently thriving having recently added a third group.

Along with the Friday group, which has been meeting in excess of 30 years, there is a ladies group on a Tuesday and now a newly formed men's group who meet on a Wednesday. This group, albeit still small, has begun well with many laughs and enjoyable lunches for those attending. The Centre is a hive of activity on all three days!

Our 'spring theme' started early in September with a 'P' day. Customers and staff were asked to come along dressed up as something beginning with the letter 'P'. We welcomed pirates, pumpkins and even a pencil. Everyone enjoyed the day immensely!

October honoured breast cancer awareness month (pictured). The Centre was decorated 'in pink', morning teacup cakes were 'in pink' and the Customers from the Tuesday and Friday groups came glamorously dressed 'in pink'!



November is our craft month where we have many crafts planned for the Customers to take part in, as well as an 80s-themed party, which everyone is looking forward to. Watch this space for photos to follow in the next *Bulletin* edition!

If you are reading this and thinking the Outreach group is something you may like to become a part of, particularly on a Tuesday or Wednesday as these groups are small and need building up, please call me, the Coordinator on 6454 2897 or Nicola Ryan, Senior Outreach Coordinator, on 0409 167 380. We will then be able to discuss your eligibility to attend and make the appropriate arrangements.

You're most welcome to come and be a part of the fun we have! The more the merrier, as the saying goes!

PETA MCCORMACK-LUKINS OUTREACH COORDINATOR ROCKINGHAM

WILSON OUTREACH

I cannot believe we are already at the end of spring! I feel like time is flying quickly this year. I am surprised at how much has happened since we re-opened in July.

Customers have been returning to Outreach and have enjoyed the various activities that have been offered; Christmas in July was celebrated joyfully with tunes, food and laughter filling the festive air at Wilson Outreach. At the same time, we celebrated all the birthdays we missed during the COVID-19 lockdown. We had tried our best not to forget any birthdays by sending cards by snail mail to Customers.

September ended with a 'green day', where we started our planting projects. To start with, we made our decoupage pots with fabric, followed by choosing our own succulent plants and planting them in the pots. Customers got to take home their own succulent plant.

At the same time, one of our Customers. Sheila Hayfield, finally finished her long-awaited wheelbarrow miniature garden project. She had waited patiently for this project for a very long time. I was lucky enough, during a walk with my kids around my neighbourhood, to spot the wheelbarrow during verge collection one day. As the saying goes, "one man's junk is another man's treasure". Sheila was really thrilled the moment she saw me push the rusty wheelbarrow into Outreach. The wheelbarrow miniature garden can be seen in The Sanctuary Garden at the Wilson Services Centre.



We celebrated Father's Day with some raffles. The four lucky winners were Lyndee Aspey, Susan Hart, Steven McKay – all Customers – and Joseph, our handyman. Congratulations to all. On that day, we played paper aeroplane launch race, with each of the Customers making and decorating their own paper aeroplane. We also had some Father's Day jokes going around. It was a fun day.

We celebrated Halloween with games such as 'guess the weight of the pumpkin', 'Frankenstein bowling' and 'Frankenstein tic tac toe'

Since re-opening after the break, we have enjoyed a few live music events at Outreach. During our fundraising morning tea in The Sanctuary Garden, I invited Mr Scott to entertain our Customers and staff. I was really pleased to see people coming forward to sing, I mean ... they were really

actually holding the microphone! It was fabulous. And later that day, I received an email from Janet, conveying all the good feedback from the Customers regarding the event. To all Wilson Outreach staff, thank you very much for the great team work, I could not have done it all without your support and to Nicola Ryan, thanks for believing in me.

In the first week of October, we had a few students from Rossmoyne Senior High School come to entertain us with classical guitar pieces, Mozart on piano, as well as singing and cello.

Last but not least, DUO 41 (Roger and Bill), the ukulele duo, came to perform. Thanks to Joan Crossman (volunteer) who helped to organise this event.

ZURAINI HUSSAIN OUTREACH COORDINATOR WILSON

BUNBURY OUTREACH

Since the last time I was writing an article to go in the autumn *Bulletin*, life certainly took a twist for us all! Sadly, we did have to close Outreach for quite a number of weeks due to COVID-19, so many of the activities I had mentioned in my last Outreach news didn't come to fruition.

On a positive note, we were able to re-open our doors on 8 July and have been making up for lost time ever since! It has been said that Bunbury Outreach has been on fire of late ... NOT literally of course. Our monthly programs since returning have been really 'full-on' and have kept us all on our toes.

Numbers in attendance on a Wednesday have been very encouraging and we are always happy to welcome newcomers.

With the NDIS well and truly a part of our organisation we are seeing new Customers becoming a part of MSWA, and happily Outreach. With activities such as quizzes and games, as well as outings, we are always kept busy with planning. Our once-a-month outing to the coffee shops around Bunbury have become very popular for our group.

We of course adhere to social distancing as well as proper hygiene, as we all have become accustomed to. Customers are relishing the fresh air and having company while socialising over coffee.

To celebrate our return to The Hub, we had an 80s-themed party. A fantastic morning was had by all, with many dressing up for the occasion. Having the appropriate music to 'bop on with' made the day. Thank you to everyone who participated, your enthusiasm makes the work that happens behind the scenes so worth it.

Early in November, our group had their annual picnic. Always fun to be together in the great outdoors. Time for reflection, especially in the current situation the world finds itself in, to be forever grateful of the beauty that we have around us, particularly in the South West, and for us not to take it for granted. Thanks to all the staff for their extra efforts on our big day out!

Our most popular days since returning in July have been our 'art days'. Watch this space for more details to come in the next *Bulletin* due in summer. Everyone is enjoying participating with Shaun from the MSWA Social Welfare team. We certainly have some budding artists amongst us.

In closing, I would like to thank everyone who is associated with our Outreach group in Bunbury, as without you all our group would not be as successful as it is today. Take care of yourselves and here's to a happy and healthy Christmas period and a much smoother 2021 for us all at The Hub.

SUZI BARKER OUTREACH COORDINATOR BUNBURY

OUTREACH CHRISTMAS CLOSURE DATES

Outreach	Closing	Returning
Albany	Friday, 18 December 2020	Friday, 22 January 2021
Beechboro Eastside	Monday 14, December 2020	Monday, 18 January 2021
Beechboro Northside	Friday, 18 December 2020	Friday, 22 January 2021
Bunbury	Wednesday, 16 December 2020	Wednesday, 20 January 2021
Rockingham	Friday, 18 December 2020	Tuesday, 19 January 2021
Wilson	Thursday, 17 December 2020	Monday, 18 January 2021

RECENT FUN AT TREENDALE GARDENS

Residential and Respite Customers at Treendale Gardens have been enjoying a variety of activities run by our recreation support workers and volunteers.

During the recent COVID-19 lockdown many innovative ideas were put to good use to keep everyone entertained and keep our spirits up. Some of these activities are continuing, and are there to be experienced by anyone who is at Treendale, whether as a permanent resident or as someone visiting our wonderful Respite facility.

A recent Pirate Day was held with many residents and staff joining in the fun and dress up.

We are still open and have vacancies in both our beautiful Respite facility and three bedroom Holiday Unit, so if you feel the urge for a getaway to the South West please give us a call on 9725 9994 (Respite) or 9725 9209 (Residential).

PAULA KENNEDY
COORDINATOR SUPPORTED
ACCOMMODATION TREENDALE







WOULD YOU LIKE TO RECEIVE THE BULLETIN ONLINE?

Register your email address today to start receiving our monthly Vitality e-newsletter or the *Bulletin* magazine online.

Email damien.hill@mswa.org.au or call 9365 4814 and let us know your current email address, or to update your contact details.

JAYNE O'SULLIVAN 23 YEARS OF SERVICE

MSWA Customers inspired Jayne O'Sullivan every day of her 23 years of service

We recently waved goodbye to Hamilton Hill's High Support Accommodation Manager, Jayne O'Sullivan after a huge 23 years of service with MSWA.

Starting off as an Enrolled Nurse, Jayne's first role with MSWA was transporting MS patients from Mount Henry Hospital in Como when it shut its doors, to MSWA Fern River.

Jayne worked as a Care Support Worker and Senior Enrolled Nurse for many years at MSWA Fern River until taking on her first managerial position as Coordinator.

For a bit of a scenery change, Jayne began meeting MSWA Customers in their homes as a Community Access Nurse, always bringing joy and compassion to each Customer she visited.

For the last decade Jayne has been the manager of the Hamilton Hill High Support Accommodation facility. When asked what has changed over the years, Jayne said lots!

"Of course when I started working with MSWA it was only the condition multiple sclerosis that we supported, and now we support other neurological conditions, as well as aged care," said Jayne.

"There is also a lot more collaboration, communication and teamwork between departments and sites.



Thank you, Tayne.

"Technology has significantly changed over the years too, I've seen the introduction of many new computer systems. You learn to adapt quickly."

Being a manager also comes with challenges. "I was responsible for 30 staff and 11 residents, but I was well-supported. You really learn to trust your staff.

"I've honestly enjoyed every moment with MSWA. Our Customers inspire me each and every day."

While MSWA loses a gem, we wish Jayne all the best for her retirement which will include lots of time spent with family and grandchildren.

